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ABSTRACT

This paper reports on a 50-state telephone survey on the development of family policies through implementation of Public Law 99-457 (Part H), the 1986 Amendments to the Education of the Handicapped Act with emphasis on policies regarding consent, confidentiality, access to records, and dispute resolution. The survey addressed questions of family involvement in Interagency Coordinating Council activities, how families access the service system, how case management policies affect families, and what policies provide for procedural safeguards. Findings suggested that policies addressing procedural safeguards have been slow to develop with about one-third of the states still without established policies on these issues. State coordinators expressed a desire to minimize potential harm to families as a result of participation in the early intervention system, a concern about negative effects of instituting a process for administrative hearings, and a preference for mediation systems. Also noted was a lack of certainty in some states about their authority to implement policies or enforce compliance from other agencies. Although acceptance of the central role of the family was common, few of these policies have been implemented. Includes 4 references. (DB)

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Institute
for Child
and Family Policy

STATUS OF STATES' POLICIES THAT
AFFECT FAMILIES: PROCEDURAL
SAFEGUARDS P.L. 99-457, Part H
The Infants and Toddlers with
Handicaps Program

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The study also profited immensely throughout from advice, assistance and extensive editing of Gloria Harbin and Deborah Forsythe Perry. Kim Mattingly generously contributed of her expertise in producing the complex figures contained in the report. Special recognition is due to Tracey Johnson who provided the word processing expertise, patience and persistence.

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FOREWORD

A Series of Reports on the Family and P.L. 99-457 (Part H)

One of the clearest objectives of the framers of P.L. 99-457 (Part H) was their special concern for families. The intent to strengthen the family's role in planning for their own child is manifest in their expected participation in the Individual Family Service Plan, in the provision of procedural safeguards, the requirement that three parents service on the Interagency Coordinating Council, and the case management requirements to provide a single communication point for the family in its dealings with the professionals providing service for their child.

Legislative intent is one thing and the actual policy development and implementation that follows can be quite different. The Carolina Policy Studies Program undertook this study in an attempt to understand what the states were actually doing to put these ideas into practice.

The Carolina Policy Studies Program (CPSP), through a subcontract with the National Association of State Directors of Special Education (NASDSE), conducted a fifty-state survey in early Fall of 1990 on the development of family policies through implementation of P.L. 99-457 (Part H). The survey addressed questions of family involvement in Interagency Coordinating Council activities, how families access the service system, how case management policies affect families, and what policies provide for procedural safeguards. Because of the quantity of data collected, these results are in three separate reports.

This report, "Status of States' Policies that Affect Families: Procedural Safeguards," deals with policies regarding consent,

confidentiality, access to records, and dispute resolution. A second report, "Status of the States' Policies that Affect Families: Case Management," deals with the selection of case managers, qualifications and training of case managers, vehicles to monitor and supervise case managers, and financing the case management system. The third survey report, "Status of States' Policies that Affect Families: The Early Intervention System," deals with the ICC and the participation of family strengths and needs and family participation at the IFSP meeting.

The detailed reports of all the findings from this survey are available in reports from the Carolina Policy Studies Program, University of North Carolina at Chapel Hill, 136 E. Franklin Street, Chapel Hill, N.C. 27514. Refer to one of the following:

Place, P., Gallagher, J., & Eckland, J. (1991). Family Policies in State Programs for Infants and Toddlers with Handicaps: The Early Intervention System. Chapel Hill, N.C.: Carolina Policy Studies Program.

Place, P., Gallagher, J., & Eckland, J. (1991). Family Policies in State Programs for Infants and Toddlers with Handicaps: Procedural Safeguards. Chapel Hill, NC: Carolina Policy Studies Program.

Anderson, K., Place, P., Gallagher, J., & Eckland, J. (1991). Family Policies in State Programs for Infants and Toddlers with Handicaps: Case Management. Chapel Hill, N.C.: Carolina Policy Studies Program.

EXECUTIVE SUMMARY

This report on family policy for Part H of P.L. 99-457 is the third of three that details the results of a telephone interview survey of 50 state Part H coordinators. This report focuses on policies related to consent, confidentiality, access to records, and impartial hearings. Such policies have been slow to develop. About one-third of the states still do not have established policies on any of these issues. When they are addressed they appear to be adopted as a package. The expectation in some quarters that states (especially states where the State Education Agency is the lead agency) would merely adopt the policies of Part B of P.L. 94-142 on procedural safeguards appear to be unfulfilled. This may be because of some negative reactions in the states to Part B strategies such as the due process hearings.

State coordinators expressed a desire to minimize any potential harm which might come to families as a result of participation in the early intervention system, e.g., violation of the family's right to privacy. Another significant trend which emerged from the interviews was the concern about the possibility of changing the relationship between the early intervention system and families by instituting a process for administrative hearings. Many coordinators indicated through anecdotes that they were establishing a system of mediation so that they might avoid the more formal and potentially antagonistic process of a hearing.

A number of states are still not certain about their authority to implement these policies, including how to enforce compliance from other agencies. If necessary, the withholding of funds appears to be the choice adopted by many states who have reached a decision on such

matters. The requirement of family empowerment in this law has put many additional responsibilities on policymakers. From this survey, there appears to be general willingness to involve families in decision making. There appears to be an acceptance of the central role to be played by the family. Policies about procedural safeguards are being designed to protect a family's integrity and to minimize the intrusion of the early intervention system.

Few of these policies have been put into place or into operation. It seems clear that the states are going to be in an era of trial and error and many of these policy statements or decisions may be modified or changed by the direct experience of state agencies and service delivery personnel. At the present time, most of the states appear to be making a strong "good faith" effort to meet the requirements of the law in this domain.

INTRODUCTION

The CPSP has been studying states' development of policies for the Part H, Infant and Toddlers Program. This legislation (P.L. 99-457) targeted the family of the infant or toddler with special needs as a primary decision-maker about and potential recipient of early intervention services. The Institute is interested in studying the policies which are highly likely to impact directly on the families of these very young children. As part of these multiple study efforts, CPSP conducted a nation-wide survey to collect data on these topics.

RESULTS

Consent, Confidentiality, and Access

States were asked if they had written policies about procedural safeguards in the areas of consent, confidentiality, access to records, and impartial hearings. Data are contained in Table 1 for the first three of these topics. The data indicate that, in general, states tend to develop policies for procedural safeguards as a package. Almost two-thirds of the states have written policies about consent, 34 have policies about confidentiality and the same 34 have policies about access.

The Part H regulations offer states the option of adopting the state's policies for procedural safeguards used by the special education agency, i.e., Part B of the EHA, or developing policies specific to the Part H program. One might have expected more states that have the SEA as the lead agency to report having policies for procedural safeguards since they simply have to incorporate the SEA's policies into the Part H program.

Table 1
Policies Regarding Procedural Safeguards

Procedural Safeguards	Lead Agency			
	Yes/No	SEA n=18	Health n=14	Other n=18
Consent	Yes	8	12	11
	No	10	2	7
Confidentiality	Yes	9	13	12
	No	9	1	6
Access to records	Yes	9	13	12
	No	9	1	6

Such does not appear to be the case. As Table 1 shows, only half the states that have the SEA as the lead agency have adopted policies for procedural safeguards while almost all the Health agencies reported having these policies. Approximately two-thirds of the states that have Other lead agencies, reported having procedural safeguards. Some of the states that reported having policies said they adopted their agency's existing procedural safeguards.

Some states that reported incorporating existing agency policies volunteered that there were plans to review and/or revise these policies. Three Health agencies stated that they needed to review their policies and may end up revising them. One said the policies are fairly general and that they would need to develop procedures to operationalize these. Half the SEA states are reviewing the Part B

policies. One state with neither Health nor SEA as the lead agency said their policies were not specific to Part H and might need to be revised. More states might plan to review and, if necessary, revise their existing policies but data were not systematically collected about this issue.

Impartial Hearings

Coordinators in SEA states were also asked if they intended to adopt the special education's Part B procedures for their impartial hearing (often called "due process") procedures (see Figure 1). Only eight states where the SEA is the lead agency reported having policies about impartial hearings while 10 SEA states said they did not have written policies.

When asked if the Part H policies would be identical to existing Part B due process policies, 72 percent of the 18 SEA states said no, there would have to be some modifications, 17 percent said they would be identical, or they assumed they would be identical, and two states did not know. A continuum of responses was offered about basing the Part H policies on Part B, ranging from comments that the state would only modify the policies to include mediation to comments such as, "will use Part B as little as possible." Some SEA states that are planning on modifications to Part B say they want these changes because Part B is "too adversarial" or that they want "policies that are more collaborative."

A slightly different question was asked of non-SEA states since they are not in an agency currently governed by Part B requirements. These states were asked if they were considering adopting the Part B policies. As depicted in Figure 2, Health agencies do not appear to be considering the adoption of Part B policies. Most Health agency states

Figure 1
SEA States Adopting Part B Impartial Hearing Policy

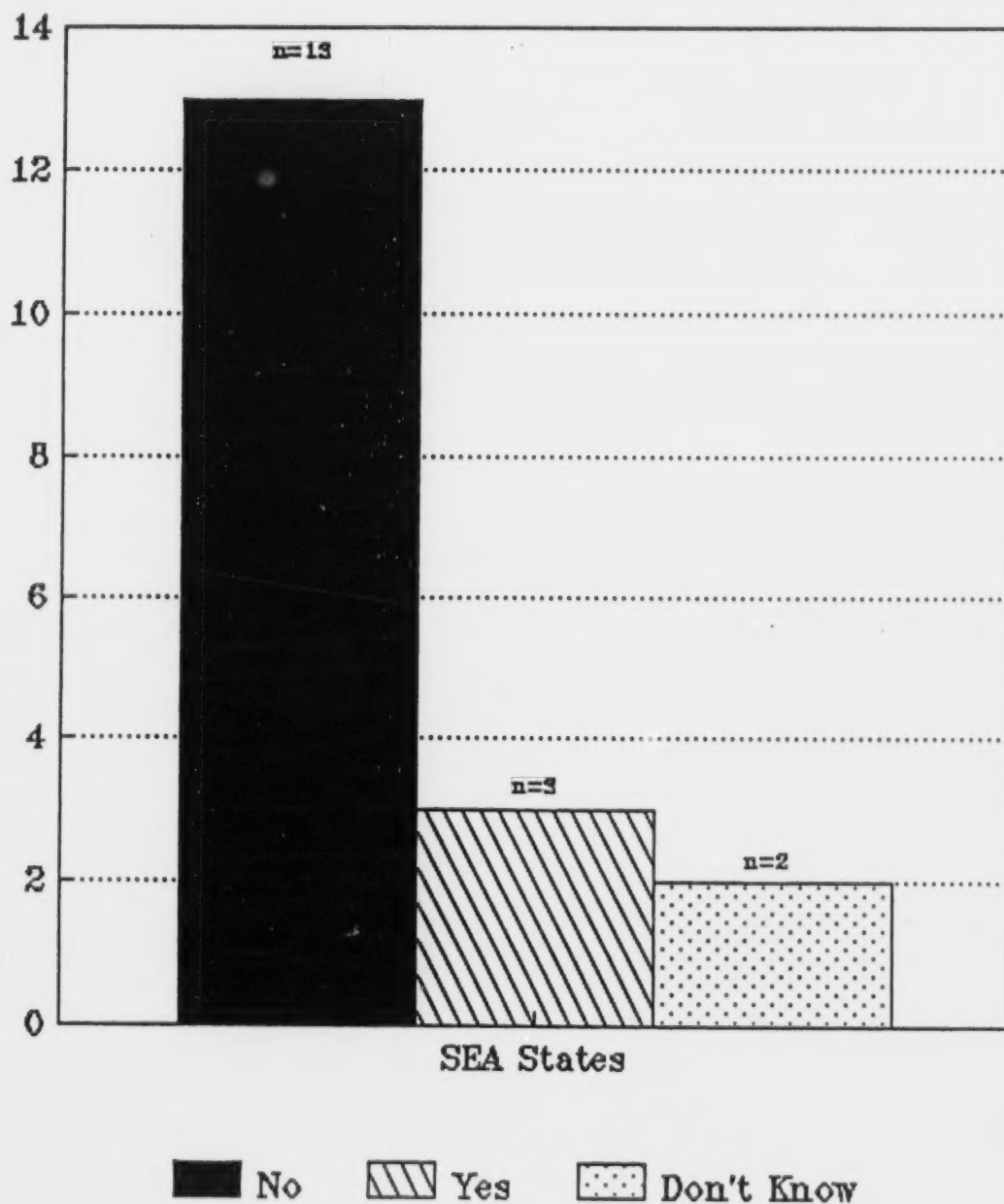
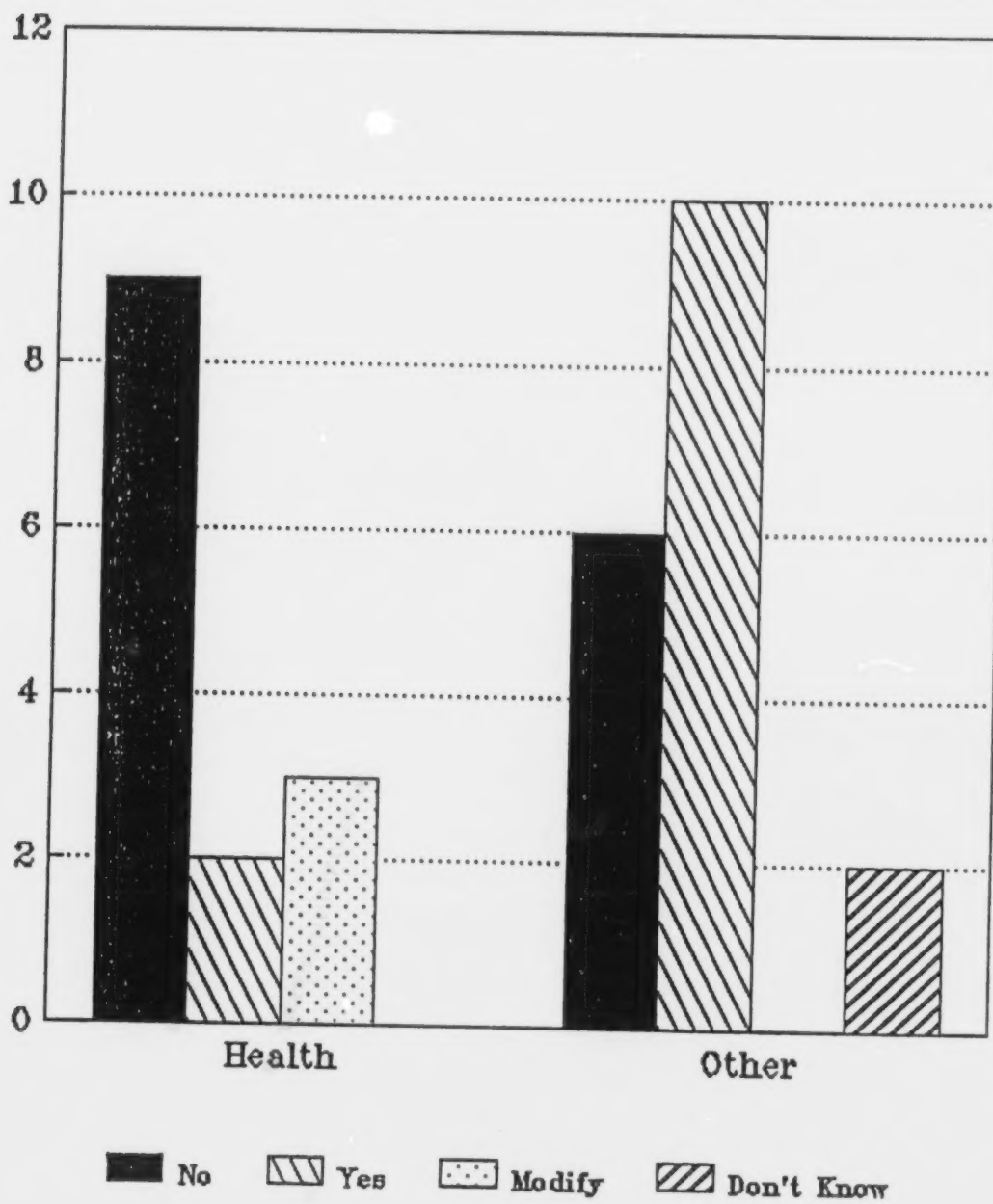


Figure 2
Non-SEA States Adopting Part B Impartial Hearing Policy

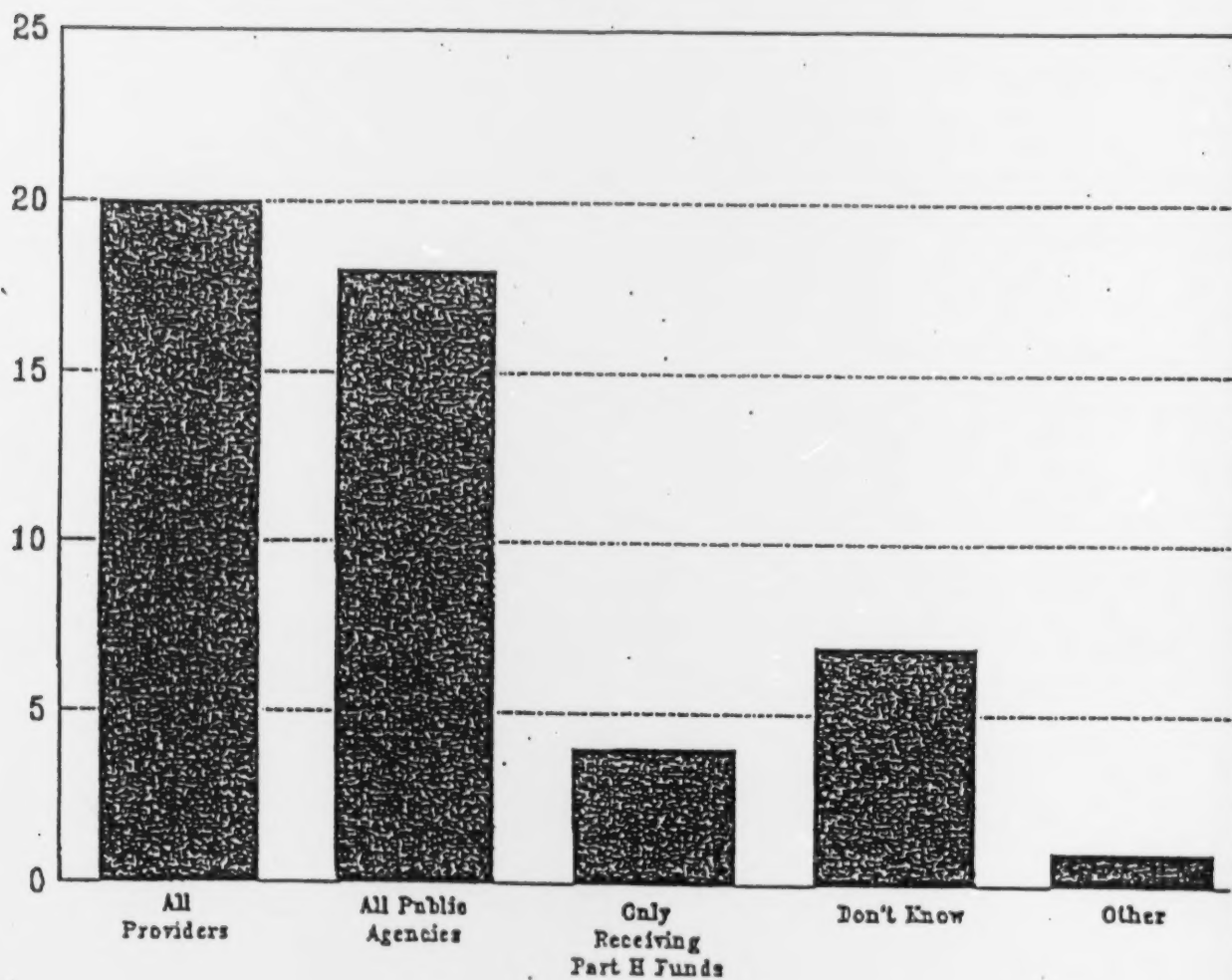


(nine) said no, they were not considering Part B at all, three will modify Part B, and two will adopt Part B (one of these said they may review this policy in the future). Details about these modifications that were volunteered included the addition of mediation and policies which are more "family friendly."

Agencies in the remaining states, on the other hand, appear to be considering adopting Part B policies. Whereas only 17 percent of the SEA states are intending to adopt Part B due process hearing policies, 56 percent of the states (ten) that do not have SEA or Health as the lead agency said that they would adopt these Part B policies. All of these states added that they would develop policies for mediation to supplement the Part B policies. One state said that they would modify Part B's timeliness and the selection of hearing officers. Coordinators in six states said they had no intention of adopting Part B policies and two states said they did not know at this time.

Compliance with Part H. Coordinators were asked to indicate which agencies they believed they had a responsibility to ensure compliance with the above procedural safeguards (see Figure 3). CPSP was interested in this information because a state can develop excellent policies for protecting parent's rights but developing policies and strategies for the implementation of these safeguards is essential to ensure that this program is supportive of families. Coordinators in 20 states explicitly stated that all providers of early intervention services, whether private or public, must comply with the Part H procedural safeguards (SEA = 5, Health = 5, Other = 10). Four coordinators indicated that they thought they had the responsibility to

Figure 3
Agencies Which Must Comply with Part H



ensure that all agencies receiving Part H funds complied with these policies.

The remaining responses (18 states) indicated the lead agency had the responsibility to ensure that all agencies which provided early intervention must comply with these procedural safeguards (SEA = 8, Health = 6, Other = 4). However, clarification of the coordinator's definition of "agency" was not systematically obtained at the beginning of the survey, as the importance of this clarification did not become apparent until after the survey began. (If a coordinator mentioned anything about private providers, that response was included with the 20 states above.) Further investigation would be necessary to determine if these 18 coordinators considered the term "agency" to include both private as well as public providers.

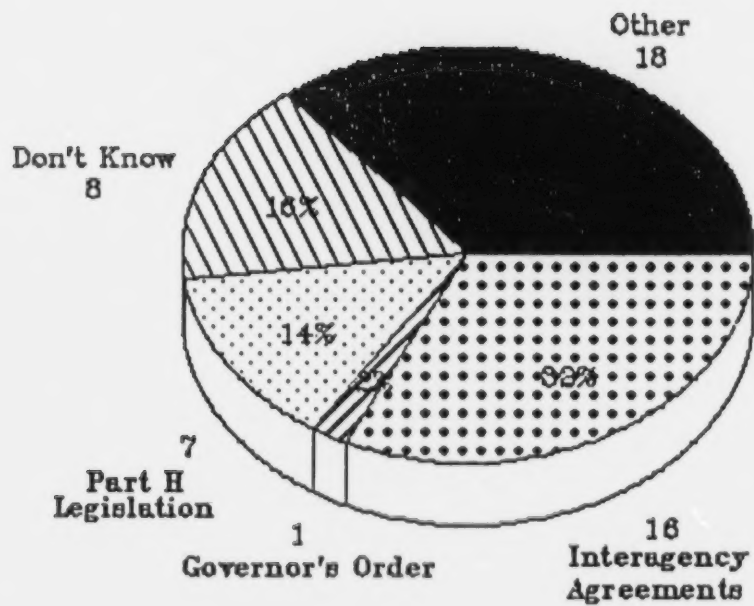
Only seven states did not provide responses to this item, that is, did not know what the policy would be, and one agency said that all early intervention services would be provided by the lead agency so the question was irrelevant.

The above policies are official in nine states (SEA = 1, Health = 2, Other = 6). Of these, eight said they had an obligation to ensure compliance by all agencies which provide early intervention. The remaining state felt this question was irrelevant, as all early intervention services would be provided directly by the lead agency.

Lead Agency Authority

When asked how they would ensure compliance, coordinators indicated a variety of modes of authority and actions (see Figure 4). Seven states are including language specifying that the lead agency has the authority to require compliance in their Part H legislation (this is

Figure 4
Compliance Strategies



official policy in three states) and one will seek this authority through a Governor's order. Interagency agreements were identified by 16 states (this is official policy in three states) as the policy vehicle by which to ensure compliance with the Part H requirements. The coordinators in eight states do not know what their policies about this will be and 18 states offered a wide variety of other approaches to ensure compliance. Monitoring and the use of existing complaint processes were cited by all four of the lead agencies which have official policies that fall into this last category. These were also among the strategies most frequently mentioned by the remaining 14 states.

Finally, states were asked what strategies were available to meet the federal requirement that the lead agency compel the correction of any deficiencies in programs serving children under Part H. The most frequently cited strategy (16 states) was to withhold state funds from programs that are not in compliance. This is the official policy in four of these 16 states. Five states currently have or plan to have an administrative hearing system within their agency which will be used to resolve interagency disputes. Some states would like to have mediation as part of this system. The use of corrective action plans was cited as a mechanism by four states and enforcement of interagency agreements was cited by six states. Almost one-third of the states (15) did not know how they could do this. Other mechanisms identified in four states were: to have legislation to address this issue, to use mediation, to resolve the issue using a dispute resolution committee or an early intervention oversight committee.

DISCUSSION

Approximately one-third of the states had not developed policies for procedural safeguards at the time of this survey, although many Part H coordinators indicated that this was an area of great concern. Coordinators tended to emphasize the complaint resolution process when referring to procedural safeguards and they were waiting to develop policies regarding hearings. Therefore, since the survey indicates that procedural safeguards tend to be developed as a package, policy development for consent, confidentiality and access to records is also being delayed. In addition to the concerns about the administrative hearing, comments were offered about the complexity of this area to justify the delay in policy development.

The administrative hearing under Part B, the due process hearing, has obviously earned a negative reputation among some agencies. Often, Part B hearing requirements were reported as being contrary to the espoused goals of the new early intervention system. Many coordinators worried that having such a formal system would lead to interactions between the early intervention system and families similar to those they had heard of between schools and parents under the due process hearing system. Great concern was expressed about the need to develop systems of dispute resolution that would support families as conflicts are resolved. Although not systematically requested, many states volunteered that they would have mediation available to families.

Learning from past mistakes or unfortunate occurrences under the Part B practices might lead to the development of policies which better match the ideological goals of most states for early intervention, i.e., to resolve disputes without harming the relationship between the

family and the early intervention system. As one result, the Part H dispute resolution system may include more options than the Part B system has traditionally provided. Coordinators spoke of the need to emphasize the goal of resolving disputes at the local level, i.e., between the family and the provider in dispute. If this fails, the coordinators asserted there should be many additional methods for resolving disputes so that families didn't feel that their only alternative was to file for a hearing.

Early intervention services will be provided by numerous public and private agencies. The interagency nature of this program might be expected to result in confusion and uncertainty about how the lead agency will exercise the authority to monitor the delivery of early intervention services and, if a program does not comply with Part H policies, how to correct the identified discrepancies. A survey just completed by NASDSE of the state directors of special education indicated concern about these areas (Place and Perry, 1990) as did a NASDSE seminar composed of multiple constituents (Perry, Place, & Anderson, 1990).

Part H coordinators identified multiple potential methods of monitoring and correcting discrepancies in service delivery. However, only 10 states have approved policies delegating the authority for this program to the lead agency. In addition, one-third of the states could not offer even a suggestion about how they might assure that program deficiencies and non-compliance are corrected by all those who provide early intervention. Concern about these two issues was a very consistent response from the coordinators. On the positive side, while great concern was expressed, many options for addressing this policy

area were proposed as possible solutions. Coordinators often expressed the need to assure that all children and families receive equitable and appropriate services and were committed to trying to assure that this happened across their states.

SUMMARY

In summary, states have undertaken, with apparent enthusiasm and zeal, a mammoth task of developing a statewide, comprehensive, coordinated, interagency, multi-disciplinary early intervention program to meet the unique needs of infants and toddlers with special needs and their families. All states are participating in the planning for this Part H system. The CPSP survey demonstrates that significant activity is occurring in each state to develop a system that will work in partnership with families to meet the needs of these very young children. As Janet Vohs, a parent of a young person with disabilities, wrote,

It is time to generate a new vision, one that empower and acknowledges not only people with disabilities, but all of us. As human beings, it disempowers us to tolerate a society in which some of us are not valued and by which our humanness is not fully embraced. Humanness brings certain universal desires: to contribute, to live in families, to love and be loved. Before, it was enough to do our best to fix up the broken parts as best we could. Public Law 99-457 gives each of us an opportunity to participate in the creation of a genuine vision of human worth (Vohs, 1990).

While difficulties were inherent in developing policies for procedural safeguards, coordinators often asserted that these policies must protect a family's rights, that interaction with the early intervention system should lead to support of the family and not to its detriment, and that all families and children are served in equitable and

appropriate ways. Procedural safeguards, in policy and implementation, can assist states in meeting these important goals.

Whether the policies reported in the CPSP survey result in the realization of the vision described so eloquently by Ms. Vohs remains to be seen as these policies begin to be implemented statewide. That these coordinators and their colleagues, partners in policy development, are striving to create this vision is a striking, and maybe the most important, finding of this study.

APPENDIX A

METHOD

As part of the family policies study, the National Association of State Directors of Special Education (NASDSE) conducted a second telephone survey of state Part H coordinators to identify the status of policies affecting families. This study was conducted as part of the sub- contract awarded to NASDSE by the Carolina Policy Studies Program (CPSP) at Frank Porter Graham Child Development Center, the University of North Carolina.

Input was solicited from the CPSP Family Advisory Board and state Part H coordinators to develop a draft survey protocol. In the spring of 1990, the draft was sent to the Family Advisory Board and selected Part H coordinators for review. These measures assured that the information to be collected was important and relevant to those who will be the primary recipients of the analysis.

During the summer of 1990, the survey protocol was mailed to all state Part H coordinators in 50 states and the District of Columbia. (The District of Columbia will be referred to as a state in this report.) Coordinators were called to schedule the one hour survey call at their convenience. After some initial calls it became apparent that additional clarification on a few items would contribute information that would be useful to states. Therefore, it was decided that some questions would be added to the original protocol despite the fact that these data would not be available from every state because some interviews had already been conducted. Whenever data are presented from less than the total number of states, such information is noted in the text. Verbal responses were coded and the categorized responses

were sent back to each coordinator for verification. Changes or corrections to these categorizations were made prior to the final data analysis.

All states participated except one. That state sent a letter declining participation because they did not have family policies and so could not respond to the items in the survey. For some analyses, states were categorized as having the State Education Agency (SEA), Health, or other as the lead agency. A category of "other" lead agencies was created because categorizing these agencies further might jeopardize their anonymity. The SEA was the Part H lead agency in 18 states that participated in the survey, Health was the lead agency in 14 states, and some other agency was the lead agency in 18 states.

The survey collected information in four areas of policy development most relevant to families: parent involvement on the Interagency Coordinating Council (ICC), selected components regarding access to the early intervention system, case management, and procedural safeguards. These topics were selected because they particularly involve or affect the families of infants and toddlers with special needs.

These topics have emerged as the significant issues through interviews with state agency personnel and families during CPSP case study interviews. In addition, the family advisory board substantiated that these were topics on which data should be collected.

Family involvement on the state ICC may influence the nature of policies and program practices for all families involved in early intervention. The first contacts between the family and the early intervention program may set the tone for all future interactions and so

identifying the policies and mechanisms which are to be used by families to enter the system were an important area of study for this survey. Identification of the family's strengths and needs can be a very positive experience if approached with a sense of partnership and support for families (Johnson, McGonigel, & Kaufmann, 1989) or can be unnecessarily intrusive. Therefore, these policies have an important place in this survey.

The same caution can be made about case management and so the nature and procedures of the case management system were important to study as states began to refine or develop this system. Decisions about services to be included on the IFSP will critically impact on the families receiving these services and so several questions addressed this topic. Finally, procedural safeguards must be studied to identify what policies will be available to protect a family's right to privacy, to assure that the family is the authority and primary decision-maker, and to provide a vehicle for resolving disputes.

All these topics were addressed in the CPSP survey. Because of the quantity of data collected, these results have been presented in three separate reports. Given the current status of policy development in the states, most of the policies identified in this report fall somewhere short of being "official" policy. These policies might represent a recommendation by the ICC or by the lead agency or might be current practice. When a policy has been formally adopted by a state it is identified as an official policy.

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